Cluster Headaches (ECH/CCH) and Personal Independence Payment

Completing the PIP2 ‘How your condition affects you’ Form

Provided are answers that would serve as examples for you to look at when completing your PIP form.

NOTE: Not all comments will be applicable but can give you some idea as to how the form should be completed. Number of attacks and timings etc. can be changed as appropriate.

DAILY LIVING ACTIVITIES

Q1 Preparing food – ***this descriptor examines your ability to prepare a simple meal using fresh ingredients on a regular, reliable and safe basis. If you only cook using a microwave, make mention of this. If you cannot do this due to likelihood of dropping and spilling hot foods/liquids, make that clear.***

Example answer:

For the last 4-5 years I have suffered from Chronic Cluster Headache attacks averaging 8 attacks a day, these usually last between 30 minutes and 2 hours+, during which time I am constantly using oxygen (average of 10 hours a day). These attacks are frequently made worse due to them being combined with my other neurological/mental health disorders (insert here and discuss combined symptoms, i.e. CCH making depression more difficult to manage/migraine paralysis making CCH less manageable etc)

As a result of these attacks I regularly lose my balance, drop things and could reasonably be expected to drop something hot/sharp, such as boiling water or a knife. I get tingling sensations in my hands, which again adds to the potential risk when preparing food. Additionally, my vision and memory have been adversely impacted meaning that I often forget to turn off the oven / hob both during the cooking process and after it has finished. This has resulted in (mention any accidents/burns/damage to your kitchen).

My CCH attacks occur suddenly and without warning, causing me to immediately react with pain and stop in the middle of any action. I would fall to the floor/grab my head/insert any other reaction here. The pain makes me lose sense of space and time and leaves me vulnerable to environmental or self-injury due to lack of awareness.

I usually cannot walk or see properly and I would drop anything in my hands as the sudden pain from one of these attacks causes me to physically drop and roll on the ground in the foetal position. I therefore cannot cook safely at all. Due to my cluster attacks being random, with no warning, to complete this descriptor reliably I should have constant supervision to ensure I am safe and that I do not become a danger to myself when in a kitchen.

Q2 Taking Nutrition – ***this descriptor looks at your ability to get food into your body – can you cut up food/use a knife and fork/use weighted cutlery/need a feeding tube/need a soft diet/have a mental health condition which causes low motivation to eat. If you miss meals often due to pain and fatigue, they need to know how many meals you eat per day on average and how many days per week do you manage this.***

Example answer:

I have about 8 random cluster attacks a day, during one of these attacks I will be on 100% oxygen and the extreme pain in my face and jaw prevent any possibility of eating or chewing any food. On average I skip 2 out of the standard 3 meals a day, due to either having a cluster attack or recovering from one. I cannot eat 3 meals a day reliably at all and therefore do not complete this descriptor to an acceptable standard.

These attacks result in me binge eating on junk food such as sugary sweets, cereal etc. due to my complete exhaustion and lack of energy. This style of eating does not provide me with a balanced or nutritional diet. I would require a lot of assistance from others to take my nutrition to an acceptable standard, both in prompting and supervision.

Q3 Managing Treatment – *this descriptor examines whether you need help to monitor or manage medication, treatments, therapy or appointments by the use of aids or by the help of another person. The more time spent by another person helping you manage this activity, the more points the award will be. If someone helps you with these things, try and calculate roughly how many hours per week on average they spend doing so.*

Example answer:

I currently treat my CCH with a combination of tablets, sumotriptan and oxygen. I also have counselling for the psychological impact of my condition. I currently require help to do these things to a good standard and repeatedly, and without help I would fail to do so. My carer helps me to set alarms on my phone so I remember to take my medication and they prompt me when able. My carer prepares a Dosette box for me once per week. This takes at least 10 mins per week. I cannot administer my own injections and so someone helps me to do this. I have two injections daily and the administration takes 2-3 minutes at a time, or 6 minutes per day. I need supervision when using my oxygen as when I begin to experience an attack – which has no warning – I cannot see or move to put on the mask. My carer has to bring the oxygen to me and put the mask on. This happens on average twice per day and takes 5 mins at a time, or 10 mins per day. In addition, I cannot leave the house alone due to the unexpected and severe nature of my attacks. I cannot drive so my carer drives me to my counselling appointment, waits for me during and then drives me home. The whole process including journey time takes at least 2 hours per week – 1 hour counselling and 30mins each way journey time. This means my carer spends 3 hours 52 minutes per week helping me manage my treatment and without them my condition would deteriorate.

Q4 Washing and Bathing – *this descriptor examines how much help you need to bathe yourself and maintain your hygiene on a regular and reliable basis – this could be in the form of physical assistance and motivation/prompting. If you bathed independently before having CCH, compare how often you would bathe previously to how often you manage it now. If heat is a trigger to CCH mention this.*

Example answer:

I cannot rely at all on being able to wash or bathe when I need or want to. During the attacks I cannot function at all, I am in extreme agony, cannot coordinate my movements, and I am using oxygen. After the attacks I cannot do anything until I have recovered. This takes 2-3 hours. A slight change in temperature can trigger a Cluster Attack and baths are a known trigger. For a lot of the time, when I have strong shadow symptoms, it is not safe for me to try to bathe. When I do eventually get in a bath usually I have to stop because it causes an attack, I can no longer function and have to get straight on to the oxygen. My drop response also poses a serious risk (mention if you’ve fallen in the bathroom due to quick onset of an attack. This therefore means that I do not wash acceptably as I cannot do so to an acceptable standard on a reliable basis.

The exhaustion caused by struggling daily with extreme pain and my very low mood also mean that for the rest of the time it is very difficult to motivate myself as I am so intensely afraid of triggering an attack that I do not feel physically and mentally prepared for. I therefore again cannot complete this descriptor acceptably, reliably or repeatedly. I do feel very self-conscious at times when I haven't washed for several days. I am a very proud individual and prior to this condition I would bathe at least 7 times weekly. At present, I can only do so once or twice a week at best.

Q5 Managing Toilet Needs – *this descriptor refers to urinary and bowel incontinence as well as physical barriers to getting on and off the toilet and cleaning yourself afterwards.*

Example answer:

During the Cluster Attacks the toilet is very difficult. I am uncoordinated and have impaired vision for significantly long periods of time, so I often have total urinary incontinence as I do not manage to make it to the toilet or I will miss the toilet which I am not able to clear up until sometime in the future when the attack and the recovery period are over. I therefore regularly cannot manage my toilet needs to an acceptable standard and should have assistance from others to help me manage my toilet need e.g. helping me clean up accidents and helping me to get to and stay on a toilet during attacks.

Q6 Dressing and Undressing – *this refers to your ability to physically put clothing on your upper/lower body and barriers to doing this. It also examines your ability to use manual dexterity to do zips/buttons/buckles/put on shoes and socks. If you struggle to change clothes regularly due to depression, fatigue and lack of awareness of space and time.*

Example answer:

Due to the pain and fatigue caused from having cluster attacks, I frequently don't get dressed at all as I am too tired and have a consistently low mood. I have an inconsistent sleeping pattern due to the frequency of attacks and can lose track of days and nights, meaning I often spend days in the same pyjamas/clothes I have slept in. I am in too much pain to do anything during cluster attacks and therefore I spend a large number of hours of each day completely incapacitated. I therefore often do not dress to an acceptable standard, or I cannot do so repeatedly and therefore reliably. Due to the likelihood of attacks arising, I often will be disrupted whilst attempting to get dressed by a cluster attack and it takes me an exceptionally long time to complete the task, therefore the majority of the time I cannot complete this descriptor within an acceptable time period.

Q7 Communicating – ***this examines your physical capability of expressing simple information (i.e. conveying the presence of danger in a room or building) and being able to understand simple messages from those around you. You may not have an intellectual impairment, but during cluster attacks many people may find their ability to talk or take in information significantly impacted. If you have a lot of cluster attacks, this will be applicable as you will spend the majority of your time incapable of doing these things to a safe and acceptable standard.***

Example answer:

During a cluster attack I cannot say much more than ‘yes’ or ‘no’. I would not be able to correctly recognise or communicate the presence of a hazard and therefore cannot communicate safely. I am also using oxygen so can’t talk due to using an oxygen mask or mouthpiece. Cluster attacks are so draining that I need to rest and sleep a lot. After using sumatriptan I will sleep for about 4 hours as they completely wipe me out. I therefore cannot communicate reliably at all. On average, I have 8 attacks per day. Due to the way my attacks present, often communicating to others what is happening is important but I cannot do so independently. Due to my short term memory problems I frequently forget what has been said in conversations and appointments and therefore details such as recommendations from my doctor and neurologist are often forgotten. I should therefore always have someone with me to ensure I can communicate safely, acceptably, repeatedly and reliably.

Q8 Reading – ***this descriptor looks at your ability to read based on your cognitive function and your vision. If you experience regular visual disturbances that are not corrected by glasses and these regularly impact your ability to read simple texts (i.e. signs in a hospital, instructions for cooking microwave meals etc) do make mention of this.***

Example answer:

During a cluster attack, of which I get an average of 8 per day, I cannot read or follow/understand signs and symbols. This means I cannot rely on being able to see. For large parts of every day I am completely unable to read due to the pain and impact on my vision. My eyes stream, puff up, and closes. My eye and the top of my socket are in agony and there is a sensation of extreme pressure as if someone has their thumb in my eye with all their weight behind it. I am light sensitive, in extreme agony, using my oxygen and trying to survive. When an attack is building up I become light sensitive, this can be extreme and I have to get out of light. I cannot use my phone because the light causes me such severe pain it is not possible to look at it. If I cannot get out of light, the attack itself will be much worse and the treatment does not work. I also get other long periods of photosensitivity shadow symptoms and cannot attempt to read as any light to see by hurts. I spend many hours in the dark. I therefore cannot complete this descriptor reliably at all and will need assistance from others to help me read and understand words, signs and symbols.

Q9 Engaging with others face to face –*this descriptor looks at your ability to engage with those you know as well as new people on a regular basis. If you have a mental health diagnosis which is secondary to your CCH, this is especially relevant if it stops you mixing with people. Many people with CH find it hard to engage with others because of the random nature of the attacks causing them to feel paranoid about the reactions of others when they are out and about. If you previously had an active social life but you are now isolated, make that clear. If you need to have someone with you at all times due to anxiety, make it clear why you need them and what they do for you to help you be safe. The assessor will only award points in this area if they consider you to be at risk of significant psychological distress if made to engage with people without support.*

Example answer:

During Cluster attacks it is impossible for me to engage with anyone. I cannot see, or think, I am in extreme agony and have to immediately be in the dark or the attack may get much worse. My behaviour is very strange to others because I am trapped inside a severely disabling neurological attack with excruciating pain levels. I am using my oxygen, banging my head and rocking, frequently brought to the ground with pain, unaware of my surroundings or company. During the recovery I am shattered; exhausted, traumatised, confused, disorientated, and not able to interact normally with anyone. I often have to avoid mixing and socialising because I cannot predict or cope with my attacks when out and with others. If an attack occurs in public, not only am I not safe, but it can cause serious problems. Cognitively and physically I cannot explain what is happening and my behaviour can be misinterpreted. I avoid people if I know an attack is building. I can't cope with even well-meaning people because they don't know what to do and their attempts to help cause problems. My attacks do cause severe distress to other people. The attacks interfere with my ability to be patient, explain, and be tolerant which can result in me becoming very anxious and depressed. I then get misjudged as a person because people don't understand the cause of the behaviour that they see. Before experiencing CH, I had an active social life and work life and felt confident mixing with others and socialising. I now am incredibly withdrawn and only see immediate family who understand my condition and have safeguards in place for themselves and for me. Stress can trigger attacks, so the impact of knowing I have to see strangers – i.e. at appointments – can exacerbate symptoms in the run-up. I therefore cannot mix with others reliably, it causes me a significant amount of psychological distress. I should always have social support when mixing with others to try to ensure that I can do so reliably, to try to ease my distress and to be able to explain what is happening in the case of an attack.

Q10 Making Budgeting Decisions ***– this descriptor assesses your ability to understand basic calculations involved in small purchases (i.e. can you intellectually understand how much change you would receive if buying something worth 20p out of a £1 coin) and then your ability to manage a more complex household budget without falling into debt and financial disrepair. If someone helps you with groceries, mention this. If you have fallen into debt because of neglecting your finances, mention this. Please note that this MUST be linked to your condition and impaired memory/cognition/inability to manage stress. You cannot say you cannot manage a budget if your reasoning is that a partner or a family member has always done it for you – you need to be clear that you are mentally incapable of managing this on a regular basis due to your health condition and not just personal preference.***

Example answer:

During the daily attacks I cannot do anything. The attacks leave me exhausted, weak, and confused. Also I am rarely without shadow pain. During a series of bad days I often cannot do any paperwork or budgeting because I just cannot process the thoughts required. Often I cannot see properly for hours at a time. Attacks interfere with my ability to remain orientated in time and my memory lapses cause problems as I often forget that I need to pay a bill, or that I have already paid it. I therefore cannot complete this descriptor to an acceptable standard or repeatedly and should therefore have assistance from others to ensure I manage my finances reliably. I used to manage all household expenditure and grocery budgets, but I now require help in this from my family. They have taken over my direct debits and I depend on them to keep an eye on my account to ensure I do not go overdrawn. I cannot go into supermarkets due to the strip lighting so either a family member will do this for me or they will assist me in doing online grocery shopping, which I would forget to do without their help. I have such an impaired memory because of losing track of time and place that if left to manage my own budget, I would likely neglect to pay bills as I do not open mail regularly and I struggle to answer the phone on a regular basis to service providers. Due to this self-neglect, I have accrued significant debt which is out of character for me and which causes me further stress.

MOBILITY ACTIVITIES

Q1 Planning and following journeys – ***this descriptor looks at your cognitive ability to plan, remember, understand and follow a journey safely, regularly and reliably. If you drive, this refers to your ability to follow a satnav to new places or to remember the routes to familiar places. If you use public transport, can you remember bus/train routes and manage the stresses that come along with this – paying for and retaining a ticket, getting the right bus/train in the right direction, remembering where the bus stop is, sitting next to people and behaving appropriately. If you can journey to places you know but not those you don’t know on a regular basis, make this clear.***

Example answer:

During an attack I don't even know where I am. I cannot rely on being able to cognitively or physically plan and follow a route/journey either local or longer distance, I have Cluster Attacks and shadow symptoms every day and I often cannot leave my home to go to the shop, GP surgery, or Chemist when I need to because for periods of time every day I am not able to think, see, or walk. My portable oxygen lasts only half an hour which means I cannot go very far. I can’t take the home oxygen bottle with me as it is too large and too heavy. Cluster attacks are unpredictable; I cannot use public transport because it is not safe to have an attack in that environment. I can't control stopping a vehicle, or get home if I run out of oxygen. Being in a confined space with people interfering is not safe for me or them. I cannot deal with an attack in public, the thought of it makes me extremely apprehensive because of the dangers. During an attack I am disorientated, cannot see or function cognitively which adds to my anxiety and depression, I am not safe in a strange environment. I am not able to think or speak properly to ask for help or even explain what is going on. I cannot go to busy places. When I am recovering I remain confused, disorientated, anxious and depressed. I therefore require assistance when following any routes as it is not safe for me to be alone. The fact that I often cannot make journeys means that I constantly miss out on things.

Q2 Moving Around – ***this examines your ability to use your legs to move around independently on a regular basis. This usually applies specifically to those who have conditions which affect their spine/legs and use either a wheelchair or other aids to mobilise independently. In the case of CH, you can argue that you fulfil this criteria if your balance, gait and coordination are affected for the majority of the time due to the exhausting nature of the pain and recovery times you experience. If you use walking sticks, crutches, wheelchairs or walk around your home using furniture to steady yourself, state this clearly. If you do not feel safe to walk even short distances along the street and spend most of your time at home resting, it would be fair to assume that you do not regularly move for distances longer than 10-20m at a time, based on the size of an average home. If you were active before having CCH, mention this and any effects the change in lifestyle may have left you with – loss of muscle/tone, bedsores, limb weakness, shortness of breath when walking short distances, chronic fatigue, weight gain etc.***

Example answer:

During Cluster Attacks I am not able to walk at all, my balance, coordination and control are severely impacted, I am in excruciating pain, and I have to stay in one place on the oxygen. There are occasions when an attack comes on so suddenly at such a severe level that I cannot then get to my oxygen in the next room as I simply drop and roll in agony in a foetal position on the ground. I get injuries due to disorientation, stumbling, banging into things, tripping. After attacks, during recovery I am dizzy, disorientated, confused and bone ache tired. Although I have become physically able to walk a few steps I am not able to safely walk around much at all until I am fully recovered. I am frequently confined to my bedroom or living room as I am too debilitated to even walk around at home.

General Tips and Info

When applying for PIP it is important ***not*** to apply with your best day in mind. You should instead consider your ability to carry out a task ***most of the time***- i.e. does your condition affect your ability to cook/dress/wash more than 15 days out of 30?

Working out averages

It is useful to calculate averages if your attacks vary in frequency and length. You can work out an average by keeping a diary and taking a period of time and looking at how many clusters you had and how long the lead-up, attack, and recovery period lasts. It is helpful to use at least a one month period, but even a week can be helpful if you can back it up with a diary. For example -

Mon – 2 clusters, 7 hours total inc recovery and build up

Tuesday – attack free

Wednesday – 1 cluster, 2 hours inc recovery and build up

Thursday – 5 clusters, 6 daytime hours and totally disturbed sleep pattern of 8 hours

Friday – spent the day in recovery from sleepless night, 2 clusters, 5 hours total inc recovery and build up

Saturday – 1 cluster, 2 hours inc recovery and build up

Sunday - 2 clusters, 6 hours inc recovery and build up

Total clusters for the week – 13

Total hours in attack – 36 hours, plus one totally disrupted daytime period due to sleepless night

13 clusters divided by 7 days – 1.85, rounds up to two clusters per day on average. 36 hours in pain divided by 7 days – 5.1 hours on average spent in debilitating pain per day.

You can then say, based on a standard week, you have on average two cluster headaches per day, causing you to be incapacitated by pain for at least five of your waking hours – this is not even including the full day you lost to fatigue as a result of nocturnal cluster attacks.

Reliability

The Department of Work and Pensions states that ‘If an individual cannot reliably complete an activity in the way described in a descriptor then they should be considered unable to complete it at that level’
They go on to describe reliability as follows:

‘Considering reliability involves looking at whether the claimant can complete the activity as described:

- ***Safely*** – in a manner unlikely to cause harm to themselves or to another person, either during or after completion of the activity
- ***To an acceptable standard*** – i.e. being able to perform a task well
- ***Repeatedly*** – able to repeat the activity as often as is reasonably required
- ***In a reasonable time period*** – no more than twice as long as the maximum period that a non-disabled person would normally take to complete that activity’.

Remember…

- Practice – don’t write straight on to the form. Use some paper to write and phrase your answers before putting them on the form

- Photocopy the completed form before you send it off (to remember what you wrote).

- Try to get someone to check the form over for you – preferably someone who knows you well.
- Enclose statements from medical professionals, or friends/family etc. to support your answers. This helps the assessor understand your condition from both a medical and personal perspective.

- Enclosing repeat prescriptions or a diary may also be beneficial.

- When filling in each section, if you cannot complete a task reliably (see notes above) do not just tick ‘yes’ – tick ‘no’ and explain the conditions and problems you encounter when trying to complete a task.

Just to remind you that the examples above are theoretical and you may be able to do the tasks listed - these tips are just to help you understand how to approach questions.

Additional resources – Gerard to attach online

Headache Diary

Headache Impact Test

MIDAS Test